



BRAININJURY REHABILITATION

– a health technology assessment

Summary

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Braininjury Rehabilitation – a health technology assessment; Summary

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Summary

Introduction

The acute treatment of acquired brain injury has been in focus both in Denmark and elsewhere for many years, with good results. More people survive serious trauma and diseases, which has resulted in more people living with or at risk of having complex negative health effects after acquired brain injury. These effects may appear as impaired physical, mental and social functioning. Brain injury rehabilitation includes programmes with numerous services targeting the disease or injury and the person's life situation. The objective is to reduce the negative effects of the disease or trauma and to enable the person to achieve an independent and meaningful life.

Stroke and traumatic brain injury and other types of acquired brain injury² are the main causes of acquired brain injury. According to the Danish National Patient Registry, Denmark had about 12,500 cases of hospitalization from stroke in 2009 and about 9,500 cases of hospitalization from traumatic brain injury and other forms of acquired brain injury. Some of these people need rehabilitation.

In Denmark, rehabilitation has had less systematic focus than treatment in the acute phase. This health technology assessment (HTA) therefore focuses on rehabilitation programmes after the acute phase, which organizationally include services at hospitals, at specialized regional centres, in municipalities, in independent institutions and in the home. Denmark's reform of local government structure in 2007 and the changes in the Health Act in 2006 reorganized the fields of responsibility and the division of labour between the newly created five administrative regions and 98 municipalities. In practice, the legislative framework includes six acts (the Health Act, the Employment Initiatives Act, the Act on Active Social Policy, the Social Services Act, the Special Education Act and the Act on Upper-secondary Education for Young People with Special Needs). It is therefore essential to investigate how to optimally organize brain injury rehabilitation given these changes.

Further, a comprehensive overview is needed of the evidence on the effects of the rehabilitation services in Denmark. People with acquired brain injury are a heterogeneous group with very diverse and multifaceted problems and rehabilitation needs. Many professions carry out services targeting physical, mental and social problems. This report therefore has a broad starting-point in analysing brain injury rehabilitation and the effects of such services and in assessing why some rehabilitation services achieve better results than others. This report strives not only to contribute to assessing the effects of individual types of intervention but also to identify more general principles and conceptual frameworks that influence whether brain injury rehabilitation produces positive results.

Purpose

This report is based on systematic, critical and comprehensive health technology assessment. The purpose is to provide professional advice on how brain injury rehabilitation in Denmark can be organized across the municipalities, administrative regions and the state (administrative boundaries) and across professions (multidisciplinary) such that the rehabilitation services are targeted appropriately, of uniform high quality and coherent for the people involved. The assessment includes the following analyses.

2 In Danish: tilgrænsende lidelser

Technology 1 – assessing the effects of rehabilitation interventions systematically reviews the quantitative effects of the interventions, including multidisciplinary, physical, cognitive, emotional, personality, communication and social interventions.

Technology 2 – five hypotheses on factors promoting positive results in brain injury rehabilitation systematically reviews the evidence on: client-centered approaches; working with objectives; strategies for learning; transferring knowledge and skills.

The *analysis patients and relatives* focuses on how people with brain injury and their relatives (mainly spouses) experience and cope with changes in their life situation and rehabilitation services and their experience of being reintegrated into social life.

The *analysis of organization* reviews the literature based on international experience with brain injury rehabilitation and investigates the barriers to and potential for achieving coherent programmes across and within Denmark's administrative regions and municipalities.

The *economic analysis* investigates the total costs associated with rehabilitating people with acquired brain injury, the average economic costs to society of various types of rehabilitation programmes and the economic benefits.

Target group

The main target group for this health technology assessment is the working groups and reference group for the disease management programmes³ for traumatic brain injury and stroke under the auspices of the Health Planning Unit of the National Board of Health. Other target groups include administrators, health professionals and decision-makers within brain injury rehabilitation in Denmark's administrative regions and municipalities.

Definition and scope

Rehabilitation can be defined in various ways. The newest definition used in Denmark is that of the World Health Organization (WHO): “*Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination.*”

Neither this nor any other definition of rehabilitation further delimits and determines the content of the technology (brain injury rehabilitation), since the definitions do not describe in detail the services, methods and processes included in rehabilitation. The definition, however, outlines an objective in relation to achieving and maintaining functioning in a broad sense, and rehabilitation includes a process for attaining independence and self-determination. In this sense, the definition provides a broad framework for the content of this report, and the five analyses mentioned previously emphasize the report's broad starting-point in assessing brain injury rehabilitation

WHO has created the International Classification of Functioning, Disability and Health (ICF) for assessing people's health status in relation to rehabilitation. The ICF is based on WHO's biopsychosocial model. The components of this model include functioning and contextual and personal factors. This conceptual framework together with other perspectives comprises the framework for assessing brain injury rehabilitation.

³ The disease management programmes are organizational frameworks that describe the overall multidisciplinary, intersectoral and coordinated health services provided for a given chronic disease in Denmark. The National Board of Health prepares disease management programmes for the following fields: 1) adults with traumatic brain injury and other forms of acquired brain injury, 2) adults with stroke and 3) children with traumatic brain injury and other forms of acquired brain injury and children with stroke. Group 3 is not part of the target group for this report.

The research-based approach of this report and the time frame required delimiting the health technology assessment, including in relation to the content of the disease management programmes. The following delimitations were chosen to ensure that the assessment would focus on the areas with the greatest scientific uncertainty and those in which the assessment can contribute optimally to the disease management programmes.

- This assessment focuses on rehabilitation for and not acute treatment for traumatic brain injury and stroke.
- The assessment focuses on the rehabilitation needs arising from all acute, nonprogressive diseases of the nervous system. This includes stroke, traumatic brain injury, subarachnoidal haemorrhage, infections and encephalopathy (including anoxia, such as after cardiac arrest). Finally, the assessment includes literature on primary low-grade tumours in the brain and meningioma. The HTA-assessment does not cover injury to the spinal column or the peripheral nervous system. Nor does it cover people who have progressive brain diseases such as Alzheimer disease, multi-infarct dementia, other neurodegenerative diseases such as Parkinson disease or multiple sclerosis or other types of cancer such as brain metastasis. Finally, concussion is not included.
- The assessment covers people 18 years and older.

Methods

This report investigates the HTA questions related to health technology assessment through systematic literature searches for all analyses. The only studies included as the basis for the analyses are those considered relevant and of sufficient quality based on critical assessment of the studies.

Annexes 4c, 5d, 6e and 7f show the assessment of the quality of the studies for each analysis. Evidence tables in Annexes 4b, 5c, 6d and 7e describe the studies included.

The objective of this health technology assessment is to analyse the best available evidence within these fields. The Levels of Evidence and Grades of Recommendation of the Centre for Evidence-Based Medicine in Oxford (Annex 1), which rates studies based on their design, forms the basis for grading the evidence presented in the quantitative studies. The quality of the qualitative studies included in the analyses of technology 2, patients and relatives and organization has been similarly assessed (Annex 1).

Technology 2 is bolstered by a systematic review of development and evaluation reports in Denmark. The development and evaluation reports do not generally have the status of scientific literature that has been subjected to peer review. These reports are included because they provide key knowledge on the practice of brain injury rehabilitation in Denmark.

Focus group interviews support the analysis of organization. Annexes 7b – d describe the methods.

The economic analysis also includes analysis based on registry data and reviews costs in Denmark by calculating the costs of four rehabilitation scenarios (Chapter 8).

The next section presents the main conclusions from the five analyses in the form of chapter summaries. The chapter summaries for technologies 1 and 2 in the main report have more detail than the other summaries.

Technology 1 – assessing the effects of rehabilitation interventions

The chapter tries to answer the following HTA questions.

- Which evidence can be identified for the effects of multidisciplinary rehabilitation programmes for people with acquired brain injury? Do multidisciplinary rehabilitation programmes for people with acquired brain injury produce better results? If so, how, when and for whom?
- Which evidence can be identified for the effects of interventions targeting physical, cognitive, emotional, personality, communication or social aspects in a rehabilitation programme for people with acquired brain injury?
- Which components influence the results of a rehabilitation programme for people with acquired brain injury: the intensity and length of the initiative, the severity of disease, regional or municipal level, services at a hospital or clinic or in the home?

This subsection summarizes the results of the systematic literature assessments.

Multidisciplinary rehabilitation of people with acquired brain injury

Strong evidence indicates 1) moderate to great effects from hospital-based, specialized, multidisciplinary rehabilitation of everyone with a stroke; 2) that early discharge to continuing home-based multidisciplinary rehabilitation provided by a hospital-based multidisciplinary team improves the prognosis further for people with mild to moderate stroke; 3) that continuing outpatient multidisciplinary rehabilitation after discharge from hospital has a positive effect; and 4) that the best way for multidisciplinary rehabilitation to achieve positive results is to strive towards activity-based objectives that are determined jointly with the person with acquired brain injury and his or her relatives. The positive effects of multidisciplinary rehabilitation among people with stroke have not been demonstrated beyond the first year after the onset of disease.

For people with other types of moderate to severe acquired brain injury, strong evidence indicates that subacute, intensive, hospital-based, multidisciplinary rehabilitation has positive effects, but the long-term effects have been inadequately investigated. Despite such differences as age and symptoms, it seems reasonable to assume that the positive effects of multidisciplinary rehabilitation for stroke also apply to other types of acquired brain injury. Moderate evidence indicates that a strong alliance between the rehabilitation team and the person with acquired brain injury improves the probability of positive results.

Weak to moderate evidence indicates that multidisciplinary rehabilitation programmes in the form of holistic neuropsychological programmes in the subacute or chronic phase of stroke have positive effects.

Physical intervention

Numerous specific physical interventions targeting physical dysfunctioning have been identified, including balance and walking, arm and hand functioning and other types of dysfunctioning. Moderate to strong evidence indicates that these physical interventions usually have moderate to great effects on body functions and activity. These interventions are usually activity-related, task-specific, repetitive and high-intensity. The interventions that should be offered to which people, where, when, the duration and the extent depend on numerous individual factors (such as symptoms, the severity of the brain injury, needs, cognitive ability and tiredness). Arranging a rehabilitation programme for each person with acquired brain injury requires the assessment of specialists (physicians, occupational therapists, physical therapists and nurses with specialist experience) in close collaboration with the person with acquired brain injury and

his or her relatives and depends on the resources available. Some types of intervention are more general and can be used broadly for most people with acquired brain injury. Other types of intervention are less general and can be used for selected groups. Physical intervention has the greatest positive effects in the first months after the onset of disease and seldom has positive effects past the first year after onset, even for the people with severe acquired brain injury.

Cognitive, emotional, personality and communication interventions

Moderate or strong evidence indicates that various types of psychological rehabilitation intervention have positive effects, including interventions targeting deficits in attention, unilateral spatial neglect, learning and memory, executive functions and motor apraxia. Weak to moderate evidence supports the positive effects of several types of intervention targeting emotional symptoms. Moderate to strong evidence supports the positive effects on language ability of speech training for people with aphasia: early intervention produces the best results, but intervention several years after disease onset can also have positive effects.

Social intervention

Moderate evidence indicates positive effects of various types of intervention related to the labour market, and strong to moderate evidence indicates positive results from therapy-based, multidisciplinary, team-based and occupational therapy intervention. This assessment found strong evidence for various interventions targeting relatives, who are an important part of the total rehabilitation effort.

This review shows that many types of intervention within various fields have positive effects. Nevertheless, the review of the literature also identifies interventions with well-developed evidence indicating that they have no effect and finds that the evidence is weak for some interventions such that further research is needed to clarify the effects.

For most interventions, more knowledge is needed on when, to whom, at which intensity and how often they should be applied before they can be used broadly in daily clinical practice in brain injury rehabilitation. Evidence on the effects size is generally lacking.

Technology 2 – five hypotheses on factors promoting positive results in brain injury rehabilitation

Technology 2 is based on a systematic review of: 1) the multidisciplinary interventions that have demonstrated positive effects in technology 1; 2) development and evaluation reports produced in Denmark; and 3) a systematic literature search (for qualitative studies).

The review focuses on hypotheses on the factors that promote positive results in brain injury rehabilitation. The hypotheses are related to: client-centered approaches; working with objectives; strategies for learning; strategies for transferring knowledge and skills; and the importance of multidisciplinary services.

The chapter attempts to answer the following HTA-questions relevant to assessing health technology.

- What knowledge and theoretical approaches underlie the five hypotheses: 1) in the multidisciplinary interventions included in technology 1; 2) in the development and evaluation reports produced in Denmark; and 3) in a systematic review of qua-

litative studies on brain injury rehabilitation? Finally, to what extent can this knowledge influence the achievement of positive results in brain injury rehabilitation?

Overall, the best evidence is available for working with objectives, strategies for learning and client-centered approaches, whereas less evidence is available for strategies for transferring knowledge and skills and the importance of multidisciplinary composition of rehabilitation services and teamwork. For all these areas, guidance on how to work specifically with each area when they are implemented in practice needs to be explicitly outlined.

Client-centered approaches

Although client-centered approaches has been increasingly incorporated into brain injury rehabilitation in various ways, there is no agreement on how to define a client-centered approach. Various terms are used for client-centered approaches and are attributed different meanings. Similarly, it is not always clear whether client-centered approaches refer to the genuine incorporation of user perspectives. A multidisciplinary intervention produced moderate evidence indicating that multidisciplinary teamwork strongly allied with the person with acquired brain injury has several positive effects. Qualitative research shows that client-centered approaches that incorporate the perspectives of people with acquired brain injury promote positive results in their rehabilitation, including increasing motivation and the experience of control. The analysis indicates special considerations supported by theory from which people with cognitive challenges can benefit.

Working with objectives

The literature describes working with objectives relatively thoroughly. Two reviews (of multidisciplinary interventions) found good evidence in this field. In addition, several of these interventions mention objectives without specifically investigating them. Social science research supports the hypothesis that working with objectives promotes the achievement of and maintenance of objectives. For people with cognitive problems, strategies involving objectives can specifically provide structure and maintain attention.

Strategies for learning

One multidisciplinary intervention documented the positive results of using two specific strategies for learning. Other studies emphasize several types of theoretically founded strategies for learning and how to use them in practice. The review shows that the extent to which one strategy for learning is used instead of another is not arbitrary. Finally, several evaluation reports from Denmark emphasize the concept of neuropedagogy needs further theoretical clarity.

Strategies for transferring knowledge and skills

This hypothesis maintains that the extent to which the knowledge and skills a person attains in one setting, such as a hospital, are useful in other settings in which the person operates is decisive for positive results. The positive effects also depend on whether the person with acquired brain injury is capable of transferring learning from one setting to another. This assumption is to a lesser degree investigated in the multidisciplinary interventions. Home-based training is an example of trying to solve the challenge of transfer by moving the training to the setting in which the results are used. A few studies theoretically justify (situational learning) the use of methods that increase the transfer of knowledge and skills.

Multidisciplinary services

Multidisciplinary interventions have been shown to produce positive effects. This assessment has therefore systematically investigated the extent to which knowledge can be obtained on how multidisciplinary rehabilitation services are composed and how the multidisciplinary teamwork is structured.

Multidisciplinary interventions identify three principles for determining the composition: 1) specifying the target group or programme; 2) individualizing the services; and 3) in some interventions, the intervention comprises special ideas or theories, such as in holistic neuropsychological interventions. The last type of intervention, however, has shown weak evidence for positive effects. The evaluation reports also identify these three principles. Although the multidisciplinary interventions have had positive effects, the various studies or even the development and evaluation reports have not explored how the composition influences the effects. Finally, focusing on how each intervention in a multidisciplinary programme mutually influences the others is important.

Competencies

The multidisciplinary teamwork is generally assumed to be a prerequisite for achieving positive results, but the content and nature of the teamwork are seldom defined and investigated. Nevertheless, one multidisciplinary intervention supports the hypothesis that training professionals in the competencies needed in teamwork produces positive results. The various definitions of multidisciplinary teamwork illustrate that these definitions may cover different types of collaboration, such as working together closely or in parallel. This is a key factor to incorporate when the significance of teamwork is being clarified in detail.

In addition to the previously mentioned HTA questions, this chapter seeks to answer the following HTA question.

- Which competencies are required in practice?

Only one multidisciplinary intervention explicitly discussed the competencies personnel require in carrying out their rehabilitation tasks. Professional competencies seem to be treated as a prerequisite for the interventions. In contrast, the evaluation reports from Denmark emphasize the competencies of personnel as an important factor. They emphasize specialized competencies within several fields as prerequisites for services in brain injury rehabilitation. The five hypotheses included in technology 2 cover various aspects of the relationships between the user of health services and health professionals or the relationships between health professionals. Implementing the hypotheses in practice requires integrating the development and maintenance of knowledge into the competencies of the professionals involved in rehabilitating people with acquired brain injury and ensuring an organizational framework that supports this. The need for education and training in managing cognitive and emotional problems has been specified.

Patients and relatives

The analysis of patients and relatives attempts to answer the following HTA questions.

- How do people experience acquired brain injury, and how do they cope with changes in their life situation, including the significance of this for organizing the rehabilitation of people with brain injury?
- How do relatives experience the disease, rehabilitation and changed life circumstances and what action do they take, including the significance of this for the future organization of brain injury rehabilitation?

- How do people with acquired brain injury and their relatives experience rehabilitation services, and what does this mean for the future organization of rehabilitation services?
- How do people with acquired brain injury and their relatives view and participate in life outside the home, and how should this influence rehabilitation services?

The studies reviewed describe acquired brain injury as a sudden interruption of what was otherwise expected to be a normal life course that disrupts everything related to the activities of daily living. Many people have to reorganize their daily activities. The healing process is described as a process of change filled with crises, threats to self-esteem and basic insecurity. The studies also show that establishing new ways of managing daily life and maintaining social relationships are difficult tasks requiring substantial energy. The brain injury is viewed as an injury that has effects at many levels and in the many settings in which these people live their lives. The special situation that a person's brain is injured means that the brain functions differently than before the injury. As a whole, these changes place these people in an especially vulnerable situation, especially immediately after the injury but for some also later in the course of disease. This vulnerable situation emphasizes that these people need a framework that supports opportunities for experiencing continuity.

The analysis of patients and relatives has seven main conclusions:

- The transition between institutions is considered especially challenging. The transition between the hospital and the home is described as especially difficult for both the person with acquired brain injury and relatives. The negative experiences and frustrations decline in parallel with progress, new skills and the person mastering his or her life. Changes in functioning, changes in self-esteem and fewer social relationships and leisure activities may make the people with acquired brain injury susceptible to having a more isolated life, with the risk of developing disorders such as depression.
- Interaction with health professionals and with other people such as relatives and others in the same situation plays a key role in the process of relearning skills, acquiring a new status and regaining self-respect. The analysis found that people with acquired brain injury need to be actively involved in therapeutic and educational approaches that promote the person's motivation, autonomy and self-image of being able to master his or her life situation better. The analysis thus shows that interaction with other people who are sympathetic and create opportunities enables people with acquired brain injury to develop a new positive understanding of their life situation.
- The analysis shows that relatives consider both the time immediately after the injury and later times in the course of disease as being difficult and stressful. Relatives experience loss in several areas: less time for leisure activities, themselves and social interaction. Further, some spouses find the changes in their intimate relationship to be a difficult loss. The review shows that relatives acquire psychosocial symptoms. Some experience a burden sufficient to risk becoming ill. This analysis therefore indicates that incorporating relatives in the overall rehabilitation programme is important.
- Finding and arranging relevant rehabilitation services after the inpatient phase is difficult, and this problem is often left to the patients and relatives. Studies show that people with acquired brain injury benefit from professional case managers with relevant competencies. Such individualized services may be decisive in relieving relatives, continuing follow-up contact, ensuring psychological support and linking to other treatment services.

- The analysis found that people with acquired brain injury have special difficulty in returning to the labour market, getting job training and establishing other contact in daily life. Several studies show that people with acquired brain injury need support for a very long time to be able to function in the labour market.
- Regaining an acceptable status and role in society after an acquired brain injury may be difficult. Studies indicate that people with acquired brain injury may have difficulty in fitting into the normal expected roles. Further, they may feel stigmatized, either because other people cannot see their problems or because other people have different attitudes towards people with acquired brain injury. Employment and leisure activities are thought to play a key role in regaining status and self-respect. The literature barely focuses on this problem, even though society's general attitudes towards people with acquired brain injury probably influence how these people specifically experience being reintegrated into social life.
- The studies reviewed seldom focus on people with severe brain injury and people with severe communication problems. Further, the studies barely cover bodily functions such as controlling food intake, elimination, sex and assistive devices. These circumstances mean that the analysis does not representatively portray the experience with and need for rehabilitation among people with acquired brain injury and their relatives.

Organization

The analysis of the organization of rehabilitation investigated the following HTA questions.

- How can studies in other countries contribute to establishing models for organizing coherent rehabilitation programmes for people with acquired brain injury in Denmark?
- What are the barriers to and potential for coherent rehabilitation programmes for people with acquired brain injury?
- How can coherent rehabilitation programmes for people with acquired brain injury be achieved across administrative and professional boundaries?

A systematic literature study and a qualitative interview study on the organization of rehabilitation for people with acquired brain injury identified four important barriers to establishing coherent rehabilitation programmes for people with acquired brain injury:

- inadequate coordination and integration of programmes across primary and secondary health care and internally within the municipalities;
- inadequate flexibility in the transition of the rehabilitation programmes between secondary and primary care;
- inadequate transfer of knowledge from hospitals (under the administrative regions) to municipalities; and
- inadequate neurological expertise within the municipalities, including the rehabilitation needs of people with acquired brain injury and existing relevant rehabilitation services.

The analysis of organization found the following overall key priority opportunities for creating coherent rehabilitation programmes for people with acquired brain injury.

Need for developing the content of rehabilitation plans⁴ and the opportunities for updating this within the municipalities. A rehabilitation plan that includes information on a person's total needs for multidisciplinary rehabilitation after discharge from the hospital is

4 In Danish: "genoptræningsplan" (according to the Health Act). According to "The guidance about training in communities and regions" the rehabilitation plan should comprise assessment of functioning and description of the actual needs of rehabilitation interventions.

essential to ensuring referral to relevant and high-quality rehabilitation services. The analysis concludes that rehabilitation plans need to be developed further such that all relevant aspects of the need for rehabilitation among people with acquired brain injury are described: physical, emotional, cognitive, communication and social. The analysis also emphasizes that people in outpatient rehabilitation programmes or people who need rehabilitation who are not hospitalized at the department dealing with stroke or other neurological departments need a rehabilitation plan.

Nevertheless, a rehabilitation plan cannot predict the need for rehabilitation in the long term and cannot account for changes in people's needs over time. The analysis therefore recommends that primary care strive to develop individual rehabilitation plans across the administrative levels and units involved. Such rehabilitation plans are especially relevant for people with long-term courses of disease that result in complex rehabilitation needs involving several administrative units. The existing model for action plans may inspire the efforts to establish rehabilitation plans across administrative units. Each municipality must involve relevant professionals to ensure that the rehabilitation plans are based on neurological expertise. This can be accomplished by employing such professionals in a neurological team, perhaps with several participating municipalities or through agreements to obtain services from the specialized departments of the administrative regions. Finally, preparing rehabilitation plans electronically will support the coherence of rehabilitation services.

Need for improving coordination. Coordinating efforts across hospitals and municipalities and across municipal administrative units is a fundamental part of establishing coherent rehabilitation programmes. The analysis recommends a more formalized structure for collaboration between administrative levels and units with the aim of ensuring coordination and integration of the services between disciplines and administrative levels, including early communication between the involved parties and relevant transfer of knowledge. This can be achieved by further developing existing coordinating functions such as coordination committees and health agreements between an administrative region and municipalities. Denmark has several locally based models for coordination and integration. Such models should be evaluated and the results disseminated nationally.

Second, the analysis emphasizes the need for internal communication across professions and especially across the municipal administrative units such that people with acquired brain injury are offered appropriate services at the relevant times in their course of disease. This requires coordinated efforts that can consider each person's individual course of disease and needs.

Need for structures that support the development of neurological expertise between administrative levels and especially within the municipalities. An important part of coherent rehabilitation programmes is ensuring that the parties involved are qualified to assess people's needs for rehabilitation and to assess which services are relevant for various people with individual needs. Four specific factors are mentioned: 1) ensuring relevant neurological expertise in the rehabilitation programmes; 2) formalized knowledge on the available specialized and general rehabilitation services and their quality; 3) ensuring neurological expertise within the municipalities through multidisciplinary teams (therapists, case workers etc.) such that the relevant knowledge is always available, with various types of intermunicipal collaboration supporting the acquisition of neurological expertise in Denmark's small municipalities; and 4) introducing standards for organizing brain injury rehabilitation, including standards for coordination, giving priority to

neurological expertise in the allocation of funds and supporting neurological expertise within the municipalities. These standards should enable individual solutions, with the aim of achieving the overall objectives of the standard.

Need for clarifying which public authority is responsible for the coordinated rehabilitation efforts. The analysis finds two options. 1) It should be possible to delegate the public authority responsibility to key actors (perhaps teams across administrative levels and units) to create coherence between the individual services provided across administrative units. This ensures that coherence is created between rehabilitation needs and the possibility of getting relevant services granted at the appropriate time in the course of disease. In addition, it may be necessary to clarify how the legislation involved in the services for neurological rehabilitation within municipalities may be appropriately interpreted to create a basis for coherent services across municipal administrative units. 2) Based on experience from Norway, individual action plans can be prepared for people needing neurological rehabilitation; these can guide the coordinated services not only within the municipalities but also across administrative levels. This model does not change the public authority responsibility but obligates the parties involved to participate in coherent programmes that create individually adapted rehabilitation programmes across disciplines and across organizational boundaries.

The analysis also recommends the following.

- Flexibility should be increased, with opportunities for transitional phases between the services of the administrative regions and municipalities, including the option of being rehospitalized, admission to an outpatient clinic, the opportunity to consult secondary health care after discharge and others.
- Knowledge should be compiled in the form of grouping or classifying rehabilitation services and needs in relation to relevant indicators. This will provide an organized and informed basis for making decisions on referral and support uniform quality in rehabilitation services.

Economy

The economic analysis investigates the following HTA-questions:

- What are the total (annual) costs of treatment and rehabilitation for people with acquired brain injury in Denmark from the respective perspectives of society as a whole, the administrative regions and the municipalities?
- What are the average total societal costs of a typical programme of treatment and rehabilitation for people with acquired brain injury?
- What are the economic benefits of rehabilitating people with acquired brain injury?

A person experiencing acquired brain injury in 2004 resulted in an economic loss to society of € 24,300 the first year and about € 40,000 in total for the next five years. The costs for the first year included 42 % hospital costs and similar costs for lost productivity and for municipal costs.

In 2008, when the health costs included more parameters, the total health care costs were € 14,800, including both the year of injury and the next year. During the first two years, the total costs of treatment and rehabilitation for a person with acquired brain injury were € 36,200 based on 2008 figures. None of these figures covers all costs, but they indicate that brain injury and subsequent rehabilitation result in high and long-lasting costs.

The economic analysis describes the average costs of four typical programmes of treatment and rehabilitation for a person with acquired brain injury. The programmes are very different and vary greatly in costs. The most expensive programme is for severely injured people 18-25 years old with traumatic brain injury and costs an average of € 577,000 per programme. Very few people are in this category. The most common programme for young people is for mild injury and costs about € 10,700. Treatment and rehabilitation cost about € 26,800 for older people with stroke.

The economic analysis also assesses the potential economic benefits of rehabilitating people with acquired brain injury. Such rehabilitation as a comprehensive programme could not be compared with the option of no rehabilitation. Nevertheless, some aspects of brain injury rehabilitation positively influence mortality, nursing home costs and labour market participation. Nevertheless, data are insufficient to fully analyse the cost-effectiveness of these aspects of the programmes.

Based on this, it can be cautiously concluded that early services targeting people with stroke and programmes striving to return people with acquired brain injury to the labour market are cost-effective.

The analysis concludes that treatment and rehabilitation for people with acquired brain injury are costly, and the municipalities pay for a large but variable part of this. The analysis further concludes that rehabilitation is expected to have clinical effects and economic benefits in the form of increasing people's return to the labour market and reducing their dependence on transfer payments and services from the municipalities. Neither the clinical effects nor the economic benefits of brain injury rehabilitation as an overall programme can be compared with the costs since the benefits cannot be quantified precisely enough.

Overall assessment

Based on the critical assessment of existing knowledge on brain injury rehabilitation in this report, key conclusions and cross-cutting themes are summarized as well as opportunities for and barriers to the future organization of this rehabilitation. This health technology assessment provides professional advice, with the aim of organizing the rehabilitation services for people with acquired brain injury in a targeted way and with uniform high quality for those receiving rehabilitation services.

An important question is determining the ideal content of a rehabilitation programme for people with acquired brain injury based on the latest research. This section focuses on this question.

What evidence supports the positive quantitative effects of rehabilitation interventions?

The assessment found strong evidence overall for many interventions targeting physical dysfunctioning. Moderate to strong evidence is available for some psychological interventions. Among social interventions, strong evidence supports various interventions targeting relatives, and moderate to strong evidence supports other interventions, such as those targeting labour market participation. Evidence indicates that some types of intervention do not have any positive effects, and some types have weak evidence and further research is needed to clarify the effects.

The assessment found evidence supporting numerous positive effects for the hospital-based rehabilitation of people with stroke organized in multidisciplinary teams.

Evidence also supports positive effects for earlier discharge from hospital followed by home-based rehabilitation coordinated by a specialized hospital-based team among a subgroup of people with stroke. Positive effects on functioning and return to the labour market have also been documented for dedicated multidisciplinary hospital-based rehabilitation for people with other types of acquired brain injury, although this has not been as thoroughly investigated as for people with stroke. Among multidisciplinary interventions in the chronic phase, weak to moderate evidence supports positive effects of services for treating cognitive, emotional and behavioural disturbances in the form of holistic intensive outpatient rehabilitation (see Chapter 3).

Thus, the systematic literature review shows several positive results for both single interventions and multidisciplinary interventions, and the results show that multidisciplinary teamwork is important for achieving good results. The various types of intervention can comprise parts of a rehabilitation programme depending on several individual factors.

Why is multidisciplinary collaboration effective?

The systematic literature review in the chapter on “technology 1 – assessing the effects of rehabilitation interventions” found good evidence indicating that hospital-based rehabilitation of people with acquired brain injury organized in multidisciplinary teams has positive effects. The chapter on “technology 2 – five hypotheses on factors promoting positive results in brain injury rehabilitation” investigates what causes the positive results based on specific perspectives. The literature review shows that the reasons why the multidisciplinary services have positive effects cannot be determined precisely, but the multidisciplinary interventions analysed have various characteristics that may influence the effects. First, the composition of the interventions targets well-described target groups or specific problems. Second, the composition of the interventions is individualized. Third, some interventions are created based on special theories or approaches (such as holistic neuropsychological interventions). Nevertheless, the evidence supporting holistic interventions is weak to moderate. In addition, the priorities set for which services should be started, and when, may influence the results of the overall rehabilitation programme, but the significance of this should be clarified further. The review further documents that collectively formulating objectives between the person with acquired brain injury and health professionals influences the achievement of positive results. Similarly, moderate evidence indicates that close collaboration between the person with brain damage and the multidisciplinary team can promote positive results. Teamwork is considered a prerequisite for achieving positive results, but the importance of the content and nature of the collaboration, such as whether the collaboration is interdisciplinary or multidisciplinary, has been inadequately studied.

The factors that lead to the positive results of multidisciplinary collaboration cannot be precisely determined, but the analysis finds key elements that may be part of future development and research.

More hypotheses on the factors that promote positive results

In addition to the aspects reviewed above, several factors may influence the achievement of positive results in brain injury rehabilitation. These are generally related to the interaction between the person with acquired brain injury and health professionals.

Brain injury rehabilitation has many components, and positive effects can therefore have many causes. In addition to assessing the evidence for the results of interventions, this assessment has systematically investigated selected hypotheses (as mentioned previ-

ously – client-centered approaches, strategies for learning and transfer of knowledge and skills) that are hypothesized to influence the results across the types of interventions. The analysis shows that consensus is somewhat lacking on the content of the concepts and the theoretical basis. Qualitative studies, however, show that involving service users improves such factors as motivation and the achievement of objectives, and evidence supports the positive effects of close collaboration between service users and the team in multidisciplinary intervention. The analysis of patients and relatives supports these findings by showing that people with acquired brain injury may experience more control and meaning when they participate in their own rehabilitation. Client-centered approaches in the sense of actively incorporating users' perspectives is an overall paradigm change supported by the United Nations Convention on the Rights of Persons with Disabilities and Denmark's legislation on patients' rights, which emphasize the rights of users of health services. The review shows, however, that orienting services towards service users is an area that requires systematic efforts if it is to be implemented in this sense.

People with acquired brain injury experience many transitions during a rehabilitation programme, and transferring knowledge and skills between settings is essential here. Research has not clearly determined and often neglects the importance of professional support for transferring the knowledge and skills of the person with acquired brain injury between settings. In contrast, research has shown that working with strategies for learning produces positive results, and since people with acquired brain injury have different problems, the analysis found that professionals taking several approaches is relevant. The results show that the work of the person with acquired brain injury on the effects of the injury may be viewed as a long process of learning and change, and the analysis supports how various learning strategies may contribute to people with acquired brain injury involving themselves more in the rehabilitation based on their own premises.

Overall, the findings in relation to these three cross-cutting hypotheses (client-centered approaches, strategies for learning and transfer of knowledge and skills) can contribute in different ways to the content of a rehabilitation programme but that all these areas require targeted and systematic efforts if they are to be developed and integrated.

The perspective of change in brain injury rehabilitation

The analysis of patients and relatives shows that the process of recuperating and regaining control of one's life often takes a long time. The results show that regaining skills, finding new ways and mastering new roles in relation to oneself, relatives and other social activities requires change and a new understanding of oneself. This is a process of change that involves not only the person but also his or her relatives. The future rehabilitation of people with acquired brain injury should increasingly incorporate therapeutic and professional perspectives that include redefinition and healing and thus complement rehabilitation services targeting training to overcome loss of function.

How can brain injury rehabilitation be organized optimally?

Overall, this assessment found that any further development of the quality of brain injury rehabilitation largely depends on organizational factors. This section outlines four cross-cutting themes that may influence the results of brain injury rehabilitation: improved coordination; flexibility in assessment and in granting services; neurological expertise and competencies; and quality assurance.

Improved coordination

The analysis of organization found clearly that coordinated, multidisciplinary and multisectoral intervention is needed to achieve positive, coherent rehabilitation programmes. This can generally be achieved within the existing legislative framework in Denmark. Coordination internally in both the administrative regions and municipalities is similarly decisive. Such coordination can be ensured through local agreements on establishing multidisciplinary and municipal or intermunicipal and regional teams with personnel from various administrative units who have the necessary neurological expertise and overview. The analysis found that designating a public authority to take responsibility in these coordinating teams may be relevant to ensure the appropriate and effective organization of rehabilitation programmes and to improve coherence between rehabilitation needs and rehabilitation services.

The analysis found that effort needs to be made to use and develop rehabilitation plans, such that they increasingly cover assessment of the person's need for multidisciplinary rehabilitation, including physical, cognitive, emotional, educational and social aspects. Thus, preparing models across administrative levels that ensure that all hospitalized and non-hospitalized people who need rehabilitation have a rehabilitation plan on discharge from the hospital is important. Nevertheless, a rehabilitation plan cannot account for any changes in rehabilitation needs in the long term. In addition, the results of the analysis of patients and relatives indicate the need to ensure that the rehabilitation plans incorporate the everyday perspectives of people with acquired brain injury and their relatives. This can support further efforts in primary care to develop individual rehabilitation plans across the administrative units involved. Such plans are especially relevant in long-term programmes with complex rehabilitation needs that involve several administrative units. The conclusions of the analysis of patients and relatives support the need for coordinated and coherent efforts, as the transition between institutions and especially the transition from institutions to the home can be experienced as very challenging. The analysis shows that the people with acquired brain injury may feel alone and unable to identify relevant services and that relatives often have to step in as informal coordinators. Not all relatives in this situation have the energy to take on such a task, and this does not ensure that people with acquired brain injury receive the relevant services. The analysis of patients and relatives found that these people would like a single person to act as a case manager who has relevant professional competencies (or access to people who have these) and an overview of the course of disease and the rehabilitation programme, with the person with brain damage and relatives having direct access.

Flexibility in assessment and referral

The analysis of organization found that efforts need to be made to attain more flexible organizational models to ensure that the boundaries between administrative units and levels do not prevent relevant neurological expertise from being incorporated at all stages of a rehabilitation programme and to enable rapid and easy access to renewed assessment of the progress of the person with acquired brain injury if needed. The role of general practitioners must also be integrated, especially in identifying overlooked needs for assessment and rehabilitation.

The analysis of organization found it challenging that Denmark's municipalities do not have equal opportunities, with a sufficient number of service users, to be able to offer specialized services much less fund them. Models for intermunicipal and perhaps intersectoral collaboration can contribute to solving this.

Neurological expertise and competencies

The assessment clearly indicated the need for neurological expertise at all levels in the rehabilitation programmes to ensure that rehabilitation needs and services are identified. Both the analysis of patients and relatives and the analysis of organization indicate the importance of neurological expertise in being able to reveal disabilities that are not visible. In addition, competencies are needed among professionals, who can contribute to expanding the opportunities for action among people with acquired brain injury. The assessment has not investigated what might constitute sufficient neurological expertise, but formalized programmes of education and training at the specialist level within each profession are needed to ensure adequate competencies and to develop this field further. The assessment attempted to reveal the competencies required for brain injury rehabilitation through systematic literature review, but very few studies have covered this field systematically. The issue of competencies appears more to be an implicit prerequisite for carrying out interventions in practice: for example, that personnel needs specialized competencies within such fields as stroke, traumatic brain injury and neuropsychology. The development and evaluation reports from Denmark focus considerable attention on the competencies of health personnel. They emphasize specialized competencies as a prerequisite for services in rehabilitating people with acquired brain injury and that these competencies be maintained and developed. Not only disease-specific competencies within acquired brain injury are needed but also educational competencies and competencies within client-centered approaches, work with objectives, transfer of knowledge and skills, strategies for learning and multidisciplinary collaboration. Implementing and developing practice in these areas therefore requires integrating and maintaining the development of knowledge within the competencies of professionals and creating organizational frameworks that support this. Overall, the assessment indicates that the many diverse interventions that need to be coordinated and have their priority determined require systematic focus on developing and maintaining professional competencies at all levels.

Quality assurance

The analysis of organization documents the simultaneous demand for standardization and individualization to achieve excellence in rehabilitation programmes. This analysis indicates that the apparent paradox between standardization and individualization can be solved by formulating standards, such as disease management programmes, for rehabilitating people with acquired brain injury at a general level, and this assumes space for individually tailored programmes and local based. The standards may include indicators for organization, coordination, professional competencies and multidisciplinary collaboration. The standards must be formulated at a more general level, including in relation to the professional content: for example, that a specialist physician, neuropsychologist, specially trained nurse, hearing and speech therapist and/or specialized physical therapist or occupational therapist should assess the person with acquired brain injury and his or her need for neurological rehabilitation at fixed times during the programme.

The International Classification of Functioning, Disability and Health (ICF) can similarly be viewed as a model intended to contribute to creating qualitative coherence through such measures as providing a common conceptual framework and ensuring the uniform use of terms in rehabilitation. The ICF model has been used as a perspective in the report. The systematic review of the research on the results of rehabilitation of people with acquired brain injury shows that the ICF model is still not widely used there. This could be one reason why research on activities and participation is less prominent in this field. In contrast, the analyses on technology 2, patients and relatives

and the organization of rehabilitation show that a broad perspective is necessary in brain injury rehabilitation, which can include the ICF categories of personal and contextual factors and their interaction with the other components. This assessment has not focused systematically on the extent to which the ICF terms are appropriate and useful in practice.

Is the brain injury rehabilitation cost-effective?

The analysis of economics concludes cautiously that the treatment and rehabilitation of people with brain injury is costly, with the municipalities paying for a large but variable proportion of the costs. Further, positive clinical effects and economic benefits are expected in the form of increased return to the labour market and less dependence on municipal transfer payments and services. What does this conclusion mean? The economic benefits of comprehensive rehabilitation services for people with acquired brain injury could not be determined, since data on the overall effects of such rehabilitation and the associated costs are not available. Nevertheless, the overall assessment of this rehabilitation has documented the positive effects of many diverse interventions, and considerable development potential has been demonstrated within the organization of rehabilitation, promoting the involvement of people with acquired brain injury and their relatives and interaction within and between services. This broad evidence indicates that systematically implementing and developing brain injury rehabilitation provides benefits, but this should be carried out in close connection with research on and monitoring of this rehabilitation, with knowledge being compiled on the services and their quality so that the cost-effectiveness can be calculated in the long term.

The distribution of the costs of rehabilitating people with acquired brain injury between Denmark's municipalities, administrative regions and state indicates that the current structure of fiscal incentives does not necessarily promote increased rehabilitation efforts.

Considerations on services for rehabilitating people with acquired brain injury include criteria other than economic and financial factors in the perspectives of society as a whole and of individual service users. Denmark has signed the United Nations Convention of the Rights of Persons with Disabilities, in which Articles 26 and 27 cover people's rights to habilitation and rehabilitation and to work and employment. This poses an obligation to make effective and appropriate decisions that enable people with disabilities to attain and maintain as much independence as possible. The assessment indicates how this can be realized. The analysis of patients and relatives shows that these people have an increased risk of becoming marginalized and stigmatized and may have difficulty in finding a dignified role in society after acquired brain injury. Studies show that people with acquired brain injury have increased rates of divorce and suicide. Qualitative research indicates that ensuring early and targeted intervention in the opportunities for people with acquired brain injury to actively reformulate and clarify their roles in social settings such as family, leisure activities and the labour market is a key factor that may promote inclusion instead of exclusion.

Several studies have investigated the significance of returning to work. These findings indicate that people with acquired brain injury experience returning to the labour market or job training as being difficult, but this probably plays an important role in promoting interaction with these people's surroundings such that they achieve new status and regain self-respect. This assessment found moderate to strong evidence supporting the positive effects of labour market interventions.

This assessment shows that the relatives of people with acquired brain injury experience great loss and changes in different ways in relation to their roles in the family and the time available for other social activities. Studies in the international literature show that these people have an increased risk of mental disorders (such as depression and anxiety) compared with the general population. Considerable evidence indicates that this burden is often long-lasting. Evidence is lacking on the degree of the social and economic losses of relatives associated with acquired brain injury in Denmark and elsewhere. The assessment demonstrates that relatively minor measures may have great influence and provide new knowledge, promote emotional stability and improve people's ability to manage their new life situation. This indicates the importance of incorporating and focusing on the situation of relatives throughout rehabilitation service.

Need for development and research

This assessment found evidence of positive results for many specific types of intervention and for multidisciplinary interventions and generally found a large knowledge base for the development of and further research on services in relation to the five hypotheses on the factors promoting positive results in rehabilitation (technology 2). These results should be implemented simultaneously with research on which services are used for which target groups in Denmark and how. More knowledge is also needed on how to incorporate the experience of people with acquired brain injury and their relatives in redefining and re-establishing new perspectives on life. The positive results of multidisciplinary services also demonstrate the necessity of exploring how the municipalities can achieve similar results. The assessment shows that research that demonstrates the long-term effects of rehabilitation efforts is needed. Knowledge is needed on to whom, when, for how long and at what intensity and frequency physical, psychological and social interventions should be applied. In addition, cognitive and communication interventions often lack evidence on the effects on activities, and the focus on participation is generally absent. Evidence is lacking on the magnitude of the effects, especially for psychological interventions. Finally, it is decisive to take a broad research perspective that covers approaches from the humanities, social sciences and natural sciences and explores how the activities and participation of people with acquired brain injury can be promoted at all levels, including labour market participation.

This assessment has only to a limited degree documented experiences that describe how the people with the most severe acquired brain injury participate in rehabilitation. The literature identified in this field is very limited.

Professional advice

The future organization of brain injury rehabilitation generally requires close collaboration between the municipalities, administrative regions and the state and between administrative units, including close collaboration with educational and research institutions, to implement and further develop brain injury rehabilitation.

The results of this assessment lead to the following advice for key actors in the municipalities, the administrative regions, the state and educational and research institutions in Denmark.

- Initiating a process in which the specific interventions with documented moderate or great positive effects are implemented in Denmark.
- Taking initiatives to systematically clarify the extent to which the positive results from hospital-based, multidisciplinary intervention can be transferred to other administrative levels, such as municipalities.

- The training offered should be of a certain intensity.
- Rehabilitation should begin as early as possible, including after discharge from the hospital.

People with acquired brain injury and their relatives

- People with acquired brain injury who have impaired insight into their illness and communication and cognitive problems should be ensured special consideration, both organizationally and in the professional intervention at all levels in rehabilitation services, such that their needs are identified and they are offered relevant services.
- There should be systematic focus on client-centered approaches that genuinely involve the perspectives of people with acquired brain injury and their attitudes towards rehabilitation services.
- Structures should be developed throughout rehabilitation programmes that can contribute to involving relatives and offering them relevant services.

Organization and quality assurance

- Coordination should be developed between the municipalities, the administrative regions and the state and between the administrative units in municipalities by:
 - further developing existing coordinating functions such as municipal coordinators, coordination and integration committees, health agreements between administrative regions and municipalities and establishing formalized meetings and coordination functions;
 - developing rehabilitation plans so they are appropriate and flexible throughout the entire course of disease for services provided by the administrative regions and municipalities, including the assessment of the need for cognitive, language, behaviour and social rehabilitation, such that the process includes the people with acquired brain injury and their perspectives;
 - establishing structures across and within municipalities that overcome the barriers posed by the varying responsibilities of administrative units and levels in offering relevant rehabilitation services; and
 - establishing flexible models between municipalities, the administrative regions and the state and across municipalities that ensure rapid, continuing and specialized assessment by physicians, neuropsychologists, speech therapists and occupational and physical therapists of the rehabilitation needs of people with acquired brain injury.
- Establishing structures that contribute to finding, developing and maintaining specialized neurological expertise at all levels of organization and competencies in rehabilitation programmes.
- Rehabilitation services should be standardized in Denmark, but local adjustment should still be possible. Standardization may include organization, the need for competencies, ensuring the quality of individual rehabilitation programmes and ensuring the involvement of the person with acquired brain injury and relatives.

Research and development

- Research and development are needed in the following areas:
 - how the positive results from this assessment can be implemented in practice in Denmark;
 - the long-term effects of rehabilitation interventions and the effect size;
 - when, to whom, at what intensity and how often interventions should be applied (for most types of interventions);
 - how participation and activities can be promoted to a greater extent both as an outcome measure and in practice, with this research being carried out in close multidisciplinary collaboration;
 - how knowledge and skills can be better transferred between settings;
 - how people with acquired brain injury and their relatives can be actively involved in rehabilitation programmes; and
 - the cost–effectiveness of rehabilitating people with acquired brain injury.
- Structures are needed that support research and development services across administrative boundaries.
- The future development of practice and research should explicitly state how multidisciplinary collaboration should be carried out, including how to work with objectives, client-centered approaches and strategies for learning.
- The efforts to provide information and guidance in the knowledge centres accessible in Denmark should be developed, and measures should ensure that this knowledge is disseminated to the practice sectors.

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